

**WITHHOLDING OR
WITHDRAWING
LIFE SUSTAINING
TREATMENT**
(Discussion Paper)

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CHAPTER 1

INTRODUCTION

Advances in medical technology and knowledge have developed (and continue to do so) at a rapid pace resulting in the ability to prolong life in circumstances which would have been impossible a relatively short while ago. Now that we have the ability to prolong life, we are faced with the question of whether we should do so.

As new technologies became available, the medical profession used them to full advantage to preserve and prolong life. On the other hand, not all patients wanted aggressive life-sustaining treatment and so began the "right to die" movement. It advocated for greater patient autonomy and the right to refuse life-sustaining treatment, a right which has now been recognized in Canadian law.¹

As a result of their experience with the aggressive application of life-sustaining techniques and technologies, the medical profession came to realize that, for certain kinds of patients, the treatment had little effect and, in some cases, caused more harm in terms of suffering and indignity. It is now recognized that the aggressive administration of life-sustaining treatment, without weighing the possible harm against the possible benefit, violates ethical principles. In response, the profession has developed guidelines under which health care providers may withhold or withdraw (i.e., discontinue) life-sustaining treatment, in some cases without the consent of the patient and, at times, without their knowledge.

The debate has now shifted from the right to refuse life-sustaining treatment, which is clearly established, to the right to demand it when health care providers have determined that it is no longer appropriate. This latter "right" is not recognized by either the medical profession or at law. In fact, there is much confusion in the law about the respective rights and obligations of patients and health care providers in making decisions to withdraw or withhold life-sustaining treatment. Disputes between health care providers and patients have received a great deal of media attention and have generated public discussion. If media reports are any indication, Manitobans are unhappy with the current practice.

Professional medical guidelines and the common law, as it currently stands, give health care providers the balance of power in deciding whether to withhold or withdraw life-sustaining treatment. The source of this authority is found in the concept of futility. Health care providers are not obliged to offer or administer treatments that are, in their opinion, "futile". Futility, as a basis for end-of-life decision making, is a controversial concept because there is no generally accepted understanding of what it means.

¹*Ciarlariello v. Schacter* [1993] 2 S.C.R. 119; *Malette v. Shulman* (1990), 67 D.L.R. (4th) 321 (Ont. C.A.); *N.B. v. Hôtel Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Qué. Sup. Ct.).

The health care provider's power to decide seems at odds with the concept of patient autonomy and many people are concerned about their "loss of voice"² in the health care process. On the other hand, health care providers are concerned that increased patient control negatively impacts their professional integrity and authority to make clinical judgments. In order to satisfy the general public and the medical profession, the following broadly based issues need to be addressed:

- (1) In what circumstances is it appropriate to withhold or withdraw life-sustaining treatment?
- (2) Who should decide when it is appropriate?

A. SCOPE OF DISCUSSION PAPER

To facilitate public discussion and community/stakeholder input on these issues, the Commission reviews the current statute and common law in Canada, England and the United States. We then discuss the current practice and policy with respect to end-of-life decision making and the conflict between patients and health care providers. We devote part of the discussion to the concept of futility and the controversy around the concept as the basis for decisions to withdraw or withhold treatment and for the physician's authority to make such decisions. Particular attention is paid to the potential misuse of futility judgments with respect to the disabled and the elderly and the potential for discrimination on the basis of race, religion and culture.

We ask a number of questions throughout the paper to which we hope community and stakeholder groups will provide their views.

This paper is limited to discussion of the right to demand life-sustaining treatment and the legal authority for withdrawing or withholding life-sustaining treatment contrary to or without the consent of the patient. Much has been written on other end-of-life issues such as euthanasia and assisted suicide and it is not our intention to try to add to that debate here.

B. CONCEPTS AND TERMINOLOGY

The following legal and medical terms are frequently used in the discussion paper.

Futile or Futility

We will use the term "futile" in reference to medical care which is useless or ineffective. We refer to two types of medical futility:

²Health Care Ethics Consortium of Georgia, 1997 Task Force on Futility Report (January 1997) 4 (hereinafter referred to as "HCECG Futility Report), online: <<http://www.hcecg.org>> (date accessed: 7 May 2002).

- (a) Physiological futility (also referred to as quantitative futility) - A treatment which cannot achieve the desired goal or, in short, one which *will not work*. Physiological futility judgments are believed to involve consideration of pure and objective scientific facts and are presumed to be "value-free". Proponents of medical futility suggest that such judgments can only be made by health care providers as they require the application of clinical judgment and expertise.
- (b) Qualitative futility - A treatment which will not produce a *desirable* outcome or provide a *benefit* for the patient or, in short, one which is *not worth doing*. This type of futility judgment is presumed to be "value-laden" as the determination of what is a desired outcome or what constitutes a benefit requires a value judgment. Since values vary from person to person and such decisions require consideration of subjective and non-scientific facts, these judgments should only be made by the patient. Only the patient can decide whether a treatment is worth doing.

Health Care Provider

Any person or institution providing health care services with the power or responsibility to make decisions about patient care.

Patient

Any consumer of health care services and also includes a substitute decision-maker. A substitute decision-maker could include a court appointed committee, the Public Trustee, a health care proxy or a close relative (spouse, parent, child). We recognize that there will be some cases in which the substitute and the patient may not have identical interests or positions; however, dealing with conflict between patient and substitute decision maker is beyond the scope of this paper.

Cardiopulmonary Resuscitation (CPR)

Includes mouth-to-mouth resuscitation, chest compression, bag-and-mask positive-pressure ventilation, intubation and defibrillation.³

Do Not Resuscitate Order (DNR)

A do not resuscitate order (DNR) is an order, notation or other indication placed on a patient's chart which directs health care providers not to perform cardiopulmonary resuscitation if the patient goes into cardiac or respiratory arrest.

³Canadian Medical Association, Canadian Healthcare Association, the Canadian Nurses Association and the Catholic Health Association of Canada, "Joint Statement on Resuscitative Interventions" (1995), 153 CMAJ 1652A.

Incompetent Patient

A patient who, due to his or her youth or mental state, does not have the legal capacity to make decisions about health care. Whether a patient has legal capacity to make health care decisions (or a particular decision) will depend upon the patient's ability to understand information about his or her condition and the possible risks and consequences of proposed treatment.

Life-sustaining Treatment

A medical intervention intended to prolong the patient's life without necessarily reversing the underlying illness or injury or improving their condition (although that may happen). Intervention might include CPR, mechanical ventilation, dialysis, surgery, a feeding tube and intravenous to supply nutrition and hydration, drug therapy and antibiotics.⁴

When we talk about "withholding" life-sustaining treatment, we are referring to a decision not to start treatment that could sustain a patient's life, such as CPR. When we talk about "withdrawing" life-sustaining treatment, we mean a decision to stop a treatment that is sustaining the patient's life. For example, "turning off" a respirator or stopping dialysis treatment.

While there are differences between a decision to withhold and a decision to withdraw treatment, the moral, ethical and sometimes practical considerations underlying such decisions are often closely related and, at times, identical. For simplicity's sake, we use the *terms* interchangeably in this paper (except where the context clearly requires a choice of one or the other) while recognizing that there is a distinction between the two *concepts*.

Palliative Care

Care for individuals and families who are living with a terminal or life-threatening illness. The care is aimed at alleviating physical, emotional, psychosocial, or spiritual suffering rather than curing the underlying disease. It focuses on the comfort of the patient and includes care for the patient's family as well.⁵

Parens Patriae

Literally translated means "parent of the country" and refers to the traditional role of the Crown as guardian of persons under a legal disability including children, mentally incompetent adults and any

⁴American Medical Association, *Life Sustaining Procedures*, online: <<http://imc.gsm.com/demos/dddemo/consult/lifesust.htm>> (date accessed: 25 February 2002).

⁵Special Senate Committee on Euthanasia and Assisted Suicide, *Of Life and Death* (June 1995) 14.

person who, for any reason, is unable to act on his or her own behalf.⁶ This power is now vested in the Manitoba Court of Queen's Bench and was described by the Supreme Court of Canada as having broad application, limited only by the best interest of the person in need of protection.⁷

Permanent Vegetative State

A state of eyes-open unconsciousness with sleep-wake cycles in which the patient is incapable of awareness of themselves or their environment. A permanent vegetative state can result from a traumatic injury (car accident, assault) or a non-traumatic injury (stroke). Patients are less likely to regain consciousness after three months in a permanent vegetative state due to a non-traumatic injury or 12 months after a traumatic injury. The patient's brain continues to function to allow independent breathing and heart function so that the patient may not require life support. The average life expectancy of a patient in permanent vegetative state is 2-5 years⁸

Therapeutic Privilege

An exception to the rule that a health care provider must tell the patient about all material risks associated with a procedure. A health care provider may withhold or generalize information about risks when full disclosure might cause psychological or physical harm to the patient.

The legal validity of the privilege in Canada is uncertain. The Supreme Court of Canada referred to it in *Reibl v. Hughes*,⁹ however a subsequent Ontario trial Court decision held that the privilege is not recognized in Canadian law.¹⁰

Treatment

While we might think of "treatment" as a specific therapy for illness, the medical-legal understanding of the term is a system or process of dealing with a medical condition. Treatment includes "all steps taken to ameliorate, remedy, or lessen the effects of disease, illness, disability or disorder".¹¹

⁶*Black's Law Dictionary* (6th ed., 1990) 1114.

⁷*Re Eve* (1986), 31 D.L.R. (4th) 1 (S.C.C.). Mrs. E. sought court approval for a non-therapeutic sterilization of her mentally disabled adult daughter. The Court did not approve the procedure on the grounds that it was not required to protect Eve's physical or mental health and constituted a grave intrusion on Eve's rights.

⁸C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ 491 at 491.

⁹*Reibl v. Hughes*, [1980] 2 S.C.R. 880 at 895.

¹⁰*Meyer Estate v. Rogers* (1991), 78 D.L.R. (4th) 307 at 314 (Ont. Gen. Div.). See also B. Sniderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (2nd ed., 1995) 67-68.

¹¹Law Reform Commission of Canada, *Medical Treatment and Criminal Law* (Working Paper #26, 1980) 56.

Treatment includes things that are done as well as things that are not. Thus, withdrawing or withholding treatment forms part of the process or system of dealing with a medical condition.

C, INVITATION TO COMMENT

We hope that as many people as possible will accept our invitation to write to us and share their thoughts on the issues raised in this Discussion Paper.

Once all comments and opinions have been received, the Commission will consider them and prepare its final Report. In accordance with *The Law Reform Commission Act*, the Report will be submitted to the Minister of Justice and Attorney General for consideration.

Anyone wishing to respond to the issues raised in this Discussion Paper (or to comment on any other relevant issue) is invited to write to the Commission at the following address:

Manitoba Law Reform Commission
1210-405 Broadway
Winnipeg, MB R3C 3L6

Submissions may also be sent by fax to (204) 948-2184 or by e-mail to lawreform@gov.mb.ca. We regret that we are unable to receive oral submissions.

Unless clearly marked to the contrary, the Commission will assume that comments received are not confidential and that respondents consent to the Commission quoting from or referring to their comments, in whole or in part, and to the comments being attributed to them. However, requests for confidentiality or anonymity will be respected to the extent permitted by *The Freedom of Information Act*.

The deadline for submission is September 30, 2002.

CHAPTER 2

THE LAW IN CANADA

I think that many Canadians would have been surprised to learn that a doctor can make a "do not resuscitate order" without the consent of a patient or his or her family, yet that appears to be the current state of the law in Canada, Britain and the United States.¹

A. CONSENT GENERALLY

At common law every person has the right to consent to medical treatment, which includes the right to accept and to refuse treatment.²

The four components of consent to medical treatment are:

- consent must be given voluntarily
- a patient must have capacity [to consent]
- consent must be specific to both the treatment and the person providing it
- consent must be informed, i.e., the patient must understand the nature of the procedure, the attendant risks and benefits and any alternative treatments.³

In Manitoba, consent to treatment for incompetent patients can be obtained in a number of ways. *The Mental Health Act* and *The Vulnerable Persons Living with a Disability Act*⁴ allow for the appointment of a substitute decision-maker in certain circumstances. *The Health Care Directives Act*⁵ allows an individual to appoint a health care proxy to give consent on his or her behalf; or for the making of a health care directive giving instructions regarding medical treatment. In an emergency, health care providers can administer treatment which is necessary to preserve the patient's life and health. Where no statutorily authorized substitute is available, health care providers will seek consent from a close family member, even though there is no legal authority for family

¹*Sawatsky v. Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 362 (Man. Q.B.).

²*Reibl v. Hughes*, [1980] 2 S.C.R. 880 (consent generally); *Malette v. Shulman* (1990), 67 D.L.R. (4th) 321 (Ont. C.A.) and *N.B. v. Hôtel Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Qué. Sup. Ct.) (right to refuse medical treatment).

³B. Grainger, E. Margolese and E. Partington, "Legal and ethical considerations in blood transfusion" (1997), 156 CMAJ (11th supp.) S50 at S50-S51.

⁴*The Mental Health Act*, C.C.S.M. c. M110, ss. 28, 61 and 71; *The Vulnerable Persons Living with a Disability Act*, C.C.S.M. c. V90, s. 47.

⁵*The Health Care Directives Act*, C.C.S.M. c. H27, ss. 4-19.

members to give substitute consent.⁶ In cases where none of the above methods are available or appropriate, the Court of Queen's Bench may, under its *parens patriae* jurisdiction, consent to medical treatment which is in the patient's best interests.

B. THE RIGHT TO REFUSE VERSUS THE RIGHT TO DEMAND

The right to refuse treatment may be characterized as a negative right since it will require health care providers to refrain from treating where consent is not provided. A right to demand life-sustaining treatment would be a positive right since health care providers would be compelled to administer treatment regardless of their opinion as to whether it was appropriate.

While it seems logical to extend the right to refuse life-sustaining treatment to include the right to demand it, the latter (a positive right) does not necessarily flow from the former (a negative right).

The difference between the demands "don't touch me" and "you must touch me" is dramatic. The law has almost uniformly conceded the former but has only hesitantly recognized the latter, and only in situations related to public health and safety.⁷

Courts have little difficulty recognizing and enforcing negative rights but tend to be reluctant to recognize positive rights, particularly those which require the expenditure of money or other resources by government.⁸

In cases such as *R. v. Morgentaler* and *R. v. Parker*,⁹ the Court held that criminal prohibitions on abortion and marijuana-use deprived individuals of access to treatment. This threatened their life or health and constituted a deprivation of security of the person, contrary to section 7 of the *Canadian Charter of Rights and Freedoms*.¹⁰ These decisions were based on the (negative) right to be free from unreasonable interference in health care decisions but did not recognize a positive right of access to either abortion services or marijuana for medical purposes.

Canadian law has not recognized a legal right to life-sustaining treatment. Certainly, the law, as it currently stands, provides that a health care provider has no duty to provide treatment that is

⁶Ontario and British Columbia have enacted legislation which gives family members authority to act as substitute decision makers (*infra* at 12). In a future project, the Commission will consider whether such legislation is required in Manitoba.

⁷W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 139.

⁸See *Dunmore v. Ontario (Attorney General)*, 2001 SCC 94 and *Native Women's Assn. of Canada v. Canada*, [1994] 3 S.C.R. 627.

⁹*R. v. Morgentaler*, [1988] 1 S.C.R. 30; *R. v. Parker* (2000), 188 D.L.R. (4th) 385 (Ont. C.A.).

¹⁰*Canadian Charter of Rights and Freedoms*, being Part I of the *Constitution Act, 1982*, being Schedule B of the *Canada Act 1982* (U.K.), 1982, c. 1 (hereinafter referred to as the *Charter*).

futile and that it is for health care providers to determine when treatment is futile.

Based on the case law to date, the courts have stated that a decision not to provide treatment is exclusively within the purview of the doctor and is not a decision to be made by the courts. Thus it appears that the courts would not interfere with a medical decision not to provide treatment¹¹

Two Manitoba cases have considered conflicts between health care providers and patients over DNR orders. In *Re Child and Family Services of Central Manitoba v. Lavallee*, the Court of Appeal held that the parental consent was not required and that the physician had the exclusive authority to withhold treatment.

Whether or not such a direction [DNR] should be issued is a judgment call for the doctor to make having regard to the patient's history and condition and the doctor's evaluation of the hopelessness of the case. The wishes of the patient's family or guardians should be taken into account, but neither their consent nor the approval of a court is required.¹²

The case involved an 11-month old child (D), who had been in a persistent vegetative state since his admission to hospital at the age of three months following a severe beating. It was unlikely that D would ever regain consciousness. He would eventually contract an infection which would require "intrusive heroic measures" to save his life; however, such a procedure would only restore him to an unconscious state. Since continued treatment would not improve D's condition, his doctors wanted to place a DNR order on his chart. Child and Family Services (CFS), who apprehended D from his parents, agreed but the parents did not. As required by legislation, CFS applied for court approval of the DNR order. The Court granted the order finding it to be in D's best interest.

In overturning the lower Court's order, the Court of Appeal relied on the Massachusetts case of *Matter of Dinnerstein*¹³ in which the Appeals Court held that it was up to the health care provider to decide to withhold or withdraw treatment and not the Court. In that case, the patient's family consented to the DNR order so the Court did not address conflict between the health care provider and the patient.

A number of commentators have relied upon *Lavallee* to support the proposition that a physician has the exclusive authority to make decisions to withhold or withdraw life-sustaining treatment.¹⁴ However, there are a number of reasons why the *Lavallee* decision cannot and should

¹¹*Sawatsky v. Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 367 (Man. Q.B.).

¹²*Re Child and Family Services of Central Manitoba v. Lavallee* (1997), 154 D.L.R. (4th) 409 at 413 (Man. C.A.).

¹³*Matter of Dinnerstein*, N.E. 2d 134 at 413 (1978) (App. Ct. Mass.).

¹⁴C. Square, "Court verdict 'splendid', ethics professors says" (1998), 158 CMAJ 159, quoting Professor Arthur Shafer, Director of the Centre for Professional and Applied Ethics at the University of Manitoba: "The court ruled that patients or family members do not need to be consulted by a physician in DNR cases."

not be applied beyond the specific facts of this case.¹⁵

Lavallee involved a narrow set of facts: a very young child in a persistent vegetative state, who would certainly die and whose parents' reasons for resisting the DNR order were unclear. The Court did not consider either the *Charter* or *The Human Rights Code* (Manitoba)¹⁶ which are relevant to a broader application of the decision.

This issue arose again in *Sawatsky v. Riverview Health Centre Inc.*¹⁷ This case involved an elderly man suffering from Parkinson's disease who was admitted the Riverview Health Centre for rehabilitation and assessment. The admitting physician wanted to place a DNR order on Mr. Sawatsky's chart; however, Mrs. Sawatsky objected and the order was removed.

When Mr. Sawatsky's physician recommended a tracheotomy, Mrs. Sawatsky refused to consent and Riverview obtained an order of supervision under *The Mental Health Act* which effectively replaced Mrs. Sawatsky as substitute decision-maker.¹⁸ A few months later, Mr. Sawatsky contracted pneumonia and his physician, after reviewing his condition and prognosis, placed a DNR order on his chart without consulting or advising Mrs. Sawatsky. The Public Trustee took no position on this decision, in accordance with its policy (developed after the *Lavallee* decision) that consent of the Public Trustee would not be required unless "the proposed course of treatment involves a touching of the patient's person in a non-emergency situation."¹⁹

Mrs. Sawatsky found out about the DNR order and sought an injunction requiring Riverview to remove it. Justice Beard of the Manitoba Court of Queen's Bench granted an interim injunction and ordered two independent medical assessments of both Mr. Sawatsky's condition and the appropriateness of the DNR order. The issue became moot when Mr. Sawatsky died.

Justice Beard, in her decision to grant the injunction, identified the issues of both private and public concern as follows:

¹⁵For a detailed critique of the *Lavallee* decision, see B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba v. R.L. and S.L.H.*" (1999), 7 Health L.J. 205.

¹⁶*The Human Rights Code*, C.C.S.M. c. H175.

¹⁷*Sawatsky v. Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 (Man. Q.B.).

¹⁸In a strict legal sense, Mrs. Sawatsky did not have authority to act as substitute decision-maker for her husband since Mr. Sawatsky had not designated his wife as his proxy under *The Health Care Directives Act*. In Manitoba, health care providers consult with the next-of-kin, but there is no legal requirement to do so.

¹⁹Excerpt of a letter from the Public Trustee of Manitoba to Winnipeg hospitals dated December 16, 1997 and quoted in B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba v. R.L. and S.L.H.*" (1999), 7 Health L.J. 205 at 208. This policy was the subject of Justice Beard's disapproval in *Sawatsky*, who suggested that the Public Trustee had "completely abdicated" its responsibility to the patient: *Sawatsky v. Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 377 (Man. Q.B.). The policy has since been reversed.

- (1) in what factual circumstances can a doctor or health care facility issue a "do not resuscitate" order;
- (2) do those factual circumstances apply in this case;
- (3) can a doctor or health care facility legally issue a "do not resuscitate" order if the patient or the person entitled to consent to health care treatment for the patient refuses to consent to that order?²⁰

Justice Beard questioned whether the current legal position was definitive because previous cases did not consider the application of human rights legislation such as the *Charter* or *The Human Rights Code* (Manitoba).

Another Canadian case, *Re London Health Sciences Centre v. R.K.*, held that Canadian courts do not have the authority to exempt health care providers from civil or criminal liability for withdrawing treatment and that it was up to legislators to determine policy in this regard.

If what is being sought is a declaration that a physician has the legal right in these circumstances to withdraw life support from R.K., I am not at all certain that is a declaration a court should make. Questions such as this, involving as they do complex moral, ethical, religious, and legal issues are best dealt with in a multicultural society by Parliament rather than the courts. They lie essentially within the purview of the legislative branch of government, whose function is to decide upon and enumerate policy, and not within that of the judicial branch.²¹

Should a right to life-sustaining treatment be established, and if so, how? It has been suggested that the creation of such a right may

... rely solely on statutory law, which is generally the mechanism used to establish positive rights. Indeed, because it is the only method of creating a positive right that compels another individual to touch the person exercising the right, a legal resolution of the futility debate may lie in the hands of the federal and state legislatures....²²

The suggestion that legislation may be the only way in which a right to life-sustaining treatment can be established has prompted the Commission's review of this issue.

C. IS THERE A LEGAL BASIS FOR THE RIGHT TO TREATMENT?

²⁰*Sawatsky v. Riverview Health Centre Inc.* (1998), 167 D.L.R. (4th) 359 at 362 (Man. Q.B.).

²¹*London Health Sciences Centre v. K.(R.) (Litigation Guardian of)* (1997), 152 D.L.R. (4th) 724 at 734 (Ont. Gen. Div.).

²²W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 142.

There is no Manitoba legislation which regulates decisions to withdraw treatment. *The Health Care Directives Act* extends the common law right of consent to treatment so that a patient's wishes with respect to treatment can be honoured after the patient becomes incompetent. The Act does not create any new rights; it merely provides a mechanism for exercising existing rights to consent after incapacity.²³ There is nothing in this Act which requires a health care provider to honour a request for life-sustaining treatment which conflicts with their medical opinion.

Both Ontario and British Columbia have enacted legislation to codify the law of consent to medical treatment. Ontario's *Health Care Consent Act*²⁴ requires consent for any "treatment" including plans to withhold or withdraw care. Therefore, on a plain reading of the Act, a health care provider cannot withdraw treatment without the consent of the patient. This does not mean, however, that patients can insist on a particular treatment. British Columbia's *Health Care (Consent) and Care Facility (Admission) Act* requires consent to "health care" which does not expressly include a plan to withdraw or withhold treatment, although the definition may be broad enough to include it. The British Columbia Act also provides for "the right to select a particular form of available health care on any grounds, including moral or religious grounds".²⁵ While somewhat vague, it does suggest that a patient can request life-sustaining treatment on moral or religious grounds.

The *Criminal Code of Canada*²⁶ regulates medical treatment under the duty to provide the necessities of life²⁷ to a person already in care. The Code does not impose a duty on a health care provider to administer treatment. However, once a health care provider undertakes to do so, he or she must use reasonable knowledge, care and skill²⁸ and must continue to provide treatment where failing to do so could threaten the health or life of the patient.²⁹

A "lawful excuse" constitutes a defence to a charge of failing to provide the necessities of

²³*The Health Care Directives Act*, C.C.S.M. c. H27, s. 25: "Nothing in this Act abrogates or derogates from any rights or responsibilities conferred by statute or common law."

²⁴*Health Care Consent Act*, 1996, S.O. 1996, c. 2, Schedule A.

²⁵*Health Care (Consent) and Care Facility (Admission) Act*, R.S.B.C. 1996, c. 181, s. 4(b).

²⁶*Criminal Code of Canada*, R.S.C. 1985, c. C-46.

²⁷**215(1)** Everyone is under a legal duty ...

(c) to provide necessities of life to a person under his charge if that person

(i) is unable, by reason of detention, age, illness, mental disorder or other cause, to withdraw himself from that charge, and

(ii) is unable to provide himself with necessities of life.

²⁸**216** Every one who undertakes to administer surgical or medical treatment to another person or to do any other lawful act that may endanger the life of another person is, except in cases of necessity, under a legal duty to have and to use reasonable knowledge, skill and care in so doing.

²⁹**217** Every one who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life.

life.³⁰ The patient's request to withhold or withdraw treatment is a lawful excuse. *Lavallee* suggests that a health care provider's decision to withhold treatment on grounds of futility would also represent a lawful excuse. This is the law in other common law jurisdictions, such as California, England and New Zealand³¹ where withdrawing life sustaining treatment in certain circumstances does not breach criminal or civil law. These decisions are based upon a finding that health care providers have no duty to administer futile treatment.

Human rights legislation, such as the *Charter* and *The Human Rights Code* (Manitoba) may also affect decisions to withdraw or withhold life-sustaining treatment.

The *Charter* provides constitutional protection for certain human rights and freedom from unreasonable *state* interference in the exercise and enjoyment of those rights. Section 32(1) of the *Charter* provides that it applies to government, including "laws, regulations, policies and practices" of government.³² It does not apply to private bodies or individuals unless they exercise a government function or act as an agent of the government.³³

Under the Constitution,³⁴ authority over health care is divided between the provincial and federal governments with the provincial governments having the greater control under its power to regulate matters of a "local or private nature".³⁵ The Province has delegated some authority for the delivery of publicly funded health services to health care providers thus providers may be considered agents of the government to the extent that they are an integral part the publicly administered and funded health care system.³⁶ In other functions, such as internal management, they are not bound by the *Charter*. For example, a hospital's personnel policies are exempt from *Charter* scrutiny since the internal management of a hospital is not considered a "government" function or activity.³⁷ Conversely, in *Eldridge v. British Columbia (Attorney General)*,³⁸ the Supreme Court held that the *Charter* does apply to hospitals when they are engaged in the administration and delivery of health

³⁰*Criminal Code of Canada*, R.S.C. 1985, c. C-46, s. 215(2).

³¹*Barber v. Superior Court*, 195 Cal. Rptr. 484 (Cal. App. 1983); *Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 (H.L.); and *Auckland Area Health Board v. A.G.*, [1993] 1 N.Z.L.R. 235 (H.C.).

³²M. Jackman, "The Application of the Charter in the Health Care Context" (2000), 9 Health L. Rev. 22 at 22.

³³M. Jackman, "The Application of the Charter in the Health Care Context" (2000), 9 Health L. Rev. 22 at 25.

³⁴*The Constitution Act, 1867*, 30 & 31 Vict., c. 3 (U.K.).

³⁵M. Jackman, "Constitutional Jurisdiction over Health in Canada" (2000), 8 Health L. Rev. 95 at 96.

³⁶M. Jackman, "The Application of the Charter in the Health Care Context" (2000), 9 Health L. Rev. 22 at 24.

³⁷*Stoffman v. Vancouver General Hospital*, [1990] 3 S.C.R. 483. A physician challenged the hospital's mandatory retirement policy. The Court held that the hospital was a private entity for the purposes of internal hospital management and was not subject to *Charter* review of its personnel policy.

³⁸*Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624.

services.

In Manitoba, the publicly funded health insurance plan covers "all services rendered by a medical practitioner that are *medically required* and which are not specifically excluded by regulation."³⁹ There is no definition of the term "medically required" and no requirement that health care providers obtain Manitoba Health's approval before undertaking a treatment. Health care providers decide which services are medically required for any given patient which means that they control the patient's access to the publicly funded health care system. As suggested above, health care providers are bound by the *Charter* in exercising this public function.

The *Charter* rights which are most relevant to the provisions of health care services are the right to life, liberty and security of the person (Section 7)⁴⁰ and the right to equality before and under the law and to equal protection of the law (Section 15(1)).⁴¹

Section 7 protects the right of self-determination in health care and has been described as a fundamental right at common law.⁴² This right of self-determination is part of the right to security of the person and "encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. The right to decide what is to be done to one's own body includes the right to be free from medical treatment to which the individual does not consent. Section 15(1) of the *Charter* prohibits discrimination on both the listed and any analogous grounds.⁴³

Charter rights are subject to some limits to ensure that the exercise of rights by one person does not infringe on the rights of another. Accordingly, under section 1, all *Charter* rights are subject to reasonable limits which are "demonstrably justified in a free and democratic society." Section 7 rights are also subject to limits in accordance with "principles of fundamental justice". Limits on the rights of self-determination in health care have been recognized or proposed in the following situations:

³⁹*The Health Services Insurance Act*, C.C.S.M. c. H35., s.2(1) (definition of "medical services"); *Medical Services Insurance Regulation*, M.R. 49/93, s. 1 (definition of "insured medical services"). See also *Excluded Services Regulation*, M.R. 46/93. For judicial consideration of the term "medically required", see *Cameron v. Nova Scotia (Attorney General)* (1999), 177 D.L.R. (4th) 611 (N.S.C.A.) (challenge of the refusal to fund out-of-province fertility treatments).

⁴⁰Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

⁴¹Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

⁴²*Ciarlariello v. Schacter* [1993] 2 S.C.R. 119. A patient panicked during a medical procedure and told the doctor to stop. After further discussion with the doctor, she consented to continue; however, she suffered a reaction and was rendered a quadriplegic.

⁴³In *Law Society of British Columbia v. Andrews*, [1989] 1 S.C.R. 143, the Supreme Court of Canada held that the list of prohibited grounds of discrimination in s. 15(1) is not "exhaustive" and can include "analogous" (related or similar) grounds. The following have been held to be "analogous" grounds: citizenship (*Andrews*); "aboriginality - residence", (*Corbiere v. Canada (Minister of Indian and Northern Affairs)*, [1999] 2 S.C.R. 203); marital status (*Miron v. Trudel*, [1995] 2 S.C.R. 418); sexual orientation (*Egan v. Canada*, [1995] 2 S.C.R. 513).

- where refusing treatment might endanger the life or health of another person;⁴⁴
- where the exercise of autonomy might offend public policy; for example, the sale or donation of one's organs while living;⁴⁵
- consenting to have death "inflicted" (euthanasia or assisted suicide).⁴⁶

Withholding or withdrawing life-sustaining treatment without the patient's consent will violate the patient's right to life and security of the person because the patient may die and is deprived of control over their bodily integrity. The next question to consider is whether the deprivation of this right is in accordance with principles of fundamental justice.

In *Rodriguez*, Justice Sopinka described principles of fundamental justice as those which are vital to our societal notion of justice. The difficulty with recognizing a right to treatment is that it creates a positive obligation on the health care provider. It requires the health care provider to do something that may go against his or her professional judgment. Is a health care provider's right of professional integrity protected by the *Charter*? If there is such a right, then any right to treatment would have to be balanced against it.

Whether *The Human Rights Code* (Manitoba),⁴⁷ affects decisions to withdraw or withhold treatment depends on whether medical treatment is covered by the HRC. The goal of the HRC is to ensure *equality of opportunity* for all individuals in the provision of any "service, accommodation, facility, good, right, licence, benefit, program or privilege *available or accessible to the public* or to a section of the public" (emphasis added) [section 13(1)]. The HRC is not intended to regulate a purely private relationship - only those relationships which are open to "the public".

Section 9(1) prohibits discrimination which includes: (a) differential treatment of an individual; and (b) failure to make reasonable accommodation for the special needs of an individual, based on one or more of the listed grounds, set out in section 9(2).⁴⁸ An example in the context of health care might be the withdrawal of life-sustaining treatment from an elderly patient solely on the basis of their age.

⁴⁴*Nancy B v. Hôtel Dieu de Québec* (1992), 86 D.L.R. (4th) 385 at 391 (Qué. Sup. Ct.), quoting from Prof. J.L. Beaudoin in "Le droit de refuser d'être traité".

⁴⁵*Nancy B v. Hôtel Dieu de Québec* (1992), 86 D.L.R. (4th) 385 at 391 (Qué. Sup. Ct.), quoting from Prof. J.L. Beaudoin in "Le droit de refuser d'être traité".

⁴⁶*Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519.

⁴⁷*The Human Rights Code*, C.C.S.M. c. H175 (hereinafter referred to as "HRC").

⁴⁸The prohibited grounds of discrimination are set out in s. 9(2) and include ancestry (including colour and perceived race); nationality or national origin; ethnic background or origin; religion or creed, or religious belief, religious association or religious activity; age; sex, (including pregnancy, the possibility of pregnancy, or circumstances related to pregnancy); gender-determined characteristics or circumstances; sexual orientation; marital or family status; source of income; political belief, political association or political activity; and physical or mental disability or related characteristics or circumstances.

Section 13(1) provides an exception for discrimination for which there is "*bona fide* [good faith] and reasonable cause."

Whether or not health care providers are subject to the HRC when they are providing (or withholding) medical treatment will depend upon whether those treatments may be considered to be a service, benefit or privilege available to the public. Few cases have addressed this issue directly although at least two have found that certain medical services are available to the public.⁴⁹ Certainly, the fact that health care services are publicly funded and administered gives rise to a perception that medical treatment is a "public" service.

The meaning of phrase "services available to the public" has been considered by the Supreme Court of Canada in two cases, neither of which involved medical treatment. In *University of British Columbia v. Berg*,⁵⁰ a student alleged discrimination on the basis of mental disability when the University withheld a key to the building (all other students received keys) and did not provide her with a "rating sheet" which she needed to secure an internship. In *Gould v. Yukon Order of Pioneers*,⁵¹ the Court considered whether restricting membership in a fraternal society to men was prohibited discrimination. Justice La Forest's reasons for decision (the majority decided the case on other grounds) on whether membership was a service available to the public offers some useful comments on the nature of public and private services.

Assuming that decisions to withhold treatment fall within the scope of the HRC, a complainant (or more likely their estate) would have to establish that the decision constitutes discrimination on the basis of age, disability or one of the other grounds and that such discrimination is neither reasonable nor in good faith.

Various commissions and committees have considered end-of-life decision making and the appropriate legislative response. In the 1983, the Law Reform Commission of Canada⁵² recommended amending the *Criminal Code* to exempt health care providers who complied with their patient's refusal of life-sustaining treatment from criminal liability. The proposed amendment, which was not implemented, would have also authorized withholding treatment which was "therapeutically useless" and contrary to the patient's best interest. The Commission did not consider the impact of such an amendment on a patient who wanted life-sustaining treatment contrary to the advice of their health care provider.

In 1995, the Special Senate Committee on Euthanasia and Assisted Suicide released its report

⁴⁹*Korn v. Potter* (1996), 134 D.L.R. (4th) 437 (B.C.S.C.) (refusal to provide artificial insemination services to lesbian women was discrimination contrary to the *Human Rights Act*, S.B.C. 1984, c. 22); *Hinkel v. Wood*, [1993] B.C.C.H.R.D. No. 24, online: QL (BCHR) (dental services were considered to be customarily available to the public).

⁵⁰*University of British Columbia v. Berg*, [1993] 2 S.C.R. 353.

⁵¹*Gould v. Yukon Order of Pioneers*, [1996] 1 S.C.R. 571.

⁵²Law Reform Commission of Canada, *Euthanasia, Aiding Suicide and Cessation of Treatment* (Report #20, 1983) 32.

entitled: *Of Life and Death* The Committee identified the legal uncertainty surrounding end-of-life decision making and recommended:⁵³

- (a) formulation of national guidelines governing the withholding and withdrawing of life-sustaining treatment;
- (b) amendment of existing guidelines to match national guidelines;
- (c) enactment of legislation to recognize and clarify the circumstances in which the withholding and withdrawal of life-sustaining treatment is legally acceptable.

The Committee identified Health Canada as the body which should establish national guidelines in consultation with the provinces and territories and the relevant professional associations. In June, 2001, the federal government announced the creation of Health Canada's Secretariat on Palliative and End-of-Life Care and the provision of funding to coordinate the development of a national strategy on end-of-life care. It appears that the focus of the Secretariat will be improving the quality and availability of palliative care rather than implementing the recommendations to create national guidelines on withholding and withdrawing treatment.

In the report, the Committee addressed the issue of patient consent stating that treatment should not be withheld or withdrawn without the patient's consent unless such treatment is "futile". Futility, the Committee stated, should be narrowly defined as treatment that is, in the opinion of the health care provider, completely ineffective. Unfortunately, this reliance on futility is not very helpful, as discussed below.

In June 2000, the subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology issued its follow up report to *Of Life and Death*.⁵⁴ The subcommittee noted that none of the recommendations had been implemented but identified one development. In 1999, the Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association, and Catholic Health Association approved the *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*.⁵⁵ The Joint Statement addresses decisions to withhold and withdraw treatment.

D. CONCLUSION AND ISSUES FOR DISCUSSION

Canadian law does not clearly address end-of-life decision-making and there is much

⁵³Special Senate Subcommittee on Euthanasia and Assisted Suicide, *Of Life and Death* (June, 1995) 46.

⁵⁴Standing Senate Committee on Social Affairs, Science and Technology, "Quality End-of-Life Care: The right of every Canadian" (June 2000), report of the subcommittee of the, online: < <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm> > (date accessed: 9 May 2002).

⁵⁵Canadian Healthcare Association, *et al* "Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health care Providers and Persons Receiving Care" (June 15, 1999), on line: <<http://www.canadian-healthcare.org/chapol/joint.htm>> (date accessed: 7 May 2002).

uncertainty regarding the respective rights and obligations of health care providers and patients. This leads to the following questions (with respect to which the Commission hopes to receive input)

Question 1: What should be the nature or form of legal rules governing decisions to withdraw and withhold life-sustaining treatment?

For example:

- (a) legislative guidelines (statutes or regulations to existing or new legislation)?
- (b) amendments to existing professional guidelines?
- (c) other?

CHAPTER 3

THE LAW ELSEWHERE

A. ENGLAND

At English common law, no one may administer medical treatment without the patient's consent. No one may give consent to medical treatment on behalf of another adult. Unlike Canada, there is no mechanism by which consent can be given on behalf of an incompetent patient and the English Court no longer has *parens patriae* jurisdiction over mentally incompetent patients.¹ This has created a gap in the law of consent and would mean that incompetent patients would have no access to medical treatment. This gap has been resolved by common law rules which set out the conditions under which a health care provider may treat a patient who cannot give consent. A health care provider may administer treatment that is, in his or her opinion, necessary and in the patient's best interest.² In determining what is in the patient's best interest, the health care provider must exercise their discretion in accordance with a "respected body of medical opinion".³

If the health care provider determines that treatment is no longer in the patient's best interest, the condition precedent to his or her authority to administer treatment is gone and the health care provider must withdraw the treatment. Thus, the House of Lords decided in *Airedale NHS Trust v. Bland*,⁴ that health care providers would not be criminally or civilly liable for withdrawing treatment from a patient in a permanent vegetative state, when continued treatment was not, in the health care provider's opinion, in the patient's best interest. The patient's family agreed with the decision to withdraw treatment so there was no dispute between the health care provider and the patient.

The patient in *Bland* had been in an permanent vegetative state for 3 1/2 years and there was no possibility that he would regain consciousness as his cerebral cortex had disintegrated. Without the cortex, he could not experience any sensation or thought. The House of Lords accepted that continued existence in a permanent vegetative state was not a "benefit" and therefore continued treatment was not in the patient's best interest.

The House of Lords recognized that there is a great division in social opinion on the moral

¹*Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 at 882 (H.L.) (see judgment of Lord Browne-Wilkinson for an explanation of how English courts lost *parens patriae* jurisdiction).

²*F. v. West Berkshire Health Authority*, [1989] 2 All E.R. 545 (H.L.) (authorizing the sterilization of a mentally incompetent woman).

³*Bolam v. Friern Hospital Management Committee*, [1957] 2 All E.R. 118 (Q.B.) (involving a claim for damages arising out of electro-convulsive therapy).

⁴*Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 (H.L.) (this case report contains the decisions at all levels including Family Division, Court of Appeal and House of Lords).

and ethical aspects of the withdrawal of treatment. For that reason, the Court held that decisions to terminate treatment for a patient in a permanent vegetative state should be subject to review and endorsement by the court for "the protection of patients, the protection of doctors, the reassurance of the patients' families and the reassurance of the public."⁵ While clearly acknowledging the expertise of doctors in determining which treatments are in a patient's best interest, the court acknowledged that decisions to terminate treatment there were "exceptional circumstances" which required guidance from the court.

.. [I]n the absence of an application, the doctor who proposes the cessation of life-supporting care and treatment on the ground that their continuance would not be in the patient's best interest will have reached that conclusion himself and will be judge in his own cause unless and until his chosen course of action is challenged in criminal or civil proceedings.⁶

The law with respect to the right of a *competent* patient to demand life-sustaining treatment is unclear and has not been directly addressed at common law or by statute in England. The British Medical Association has tried to close this gap in the law with guidelines governing the withdrawal and withholding of treatment.⁷ Although these guidelines are not "law", English courts pay great deference to professional standards and practice, thus such guidelines are likely to have great influence in any case.⁸

The guidelines allow physicians to withdraw or withhold medical treatment from patients who have "no prospect of recovery", subject to a review by a "senior clinician from outside the treatment team"⁹ (this does not apply to patients in a permanent vegetative state or similar condition as per *Bland*).

In making a decision, the health care providers must consider whether treatment will "produce the desired benefit" [11.1(a)] which is defined as "restoring or maintaining the patient's health" [1.1]. If treatment cannot provide this benefit and there is no other reason to provide the treatment, it may be "ethically and legally" withdrawn [1.1].

The patient's view about what constitutes a benefit will "carry considerable weight" and the guideline encourages health care providers to honour *reasonable* requests for treatment, if only for a short time, to allow the patient to sort out their affairs, say goodbye to family and friends, etc.

⁵*Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 at 862 (H.L.) per Lord Keith.

⁶*Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 at 876 (H.L.) per Lord Lowry.

⁷British Medical Association, *Withdrawing and Withholding Life-Prolonging Medical Treatment: Guidance for Decision Making* (2nd ed., 2001), online: BMJ Publishing Group Homepage: < <http://www.bmjpg.com/withwith/ww.htm> > (last modified: 24 April 2001). Note: relevant guidelines are identified in the text in square brackets.

⁸*Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 at 871-872 (H.L.) per Lord Goff.

⁹British Medical Association, press release, Wednesday, June 23, 1999. See also guideline 22.1(a).

[11.1(a)]. While consideration of patient's wishes and goals is encouraged, the BMA maintains that the health care provider is the ultimate authority [11.1(9a) and 18.3]. Where the primary physician's decision is "seriously challenged", the guidelines suggest that a court review is advisable [18.4].

The guidelines address the allocation of scarce resources and recognize that providing life-prolonging treatment to patients who will receive no benefit may affect the resources available to treat other patients [11.1(d)]. The guidelines suggest that courts will not require health care authorities to disregard cost concerns in treatment decisions. This view is supported in *R. v. Cambridge Health Authority, Ex. p. B*¹⁰ in which the English Court of Appeal did not interfere with a health care authority's decision not to fund a third round of cancer treatment for a young patient.

The British Medical Association has also established guidelines for CPR which address DNR orders.¹¹ The DNR guidelines suggest a general presumption in favour of performing CPR unless the patient is in the final stages of a terminal illness or where the burden to the patient outweighs the benefits. The DNR guidelines specifically refer to the English *Human Rights Act, 1998* and confirm that DNR policies and decisions must conform to the rights established by the Act. *The Human Rights Act, 1998* incorporates the majority of human rights contained in the *European Convention on Human Rights*¹² into English law. Like the *Charter*, this Act requires that public authorities act in accordance with certain human rights¹³ and that all statutes be interpreted in accordance with those rights.

Public authorities expressly include "the Department of Health, health authorities, Health Trusts, Primary care Groups and Trusts in England, Primary Care Trusts in Scotland, Local Health Groups in Wales and the equivalent bodies, still to be established, in Northern Ireland." The BMA takes the position that individual doctors working for the National Health Service are bound and that private doctors "may" also be included. The BMA goes on to suggest that even if private doctors are not considered public authorities for the purposes of the Act, good practice requires that their decisions comply with it.¹⁴

Recognizing the difficulty in defining "futility" with precision, the DNR guidelines set out

¹⁰*R. v. Cambridge Health Authority, ex parte B.*, [1995] 2 All E.R. 129 (C.A.).

¹¹British Medical Association, "Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (U.K.), and the Royal College of Nursing" (March, 2001), online: <<http://bma.org.uk>> (date accessed: 7 May 2002) (hereinafter referred to as "DNR guidelines").

¹²British Medical Association, "The Impact of the Human Rights Act 1998 on medical decision making" (October 2000), online: <<http://web.bma.org.uk>> (date accessed: 7 May 2002).

¹³Including rights to life, security of the person, respect for privacy, freedom from torture and inhuman or degrading treatment, freedom of thought, conscience and religion, freedom of expression and the freedom from discrimination in the exercise of these rights.

¹⁴British Medical Association, "The Impact of the Human Rights Act 1998 on Medical Decision Making" (October 2000), on line: <<http://web.bma.org.uk>> (date accessed: 7 May 2002).

a number of factors to be considered when determining whether DNR orders are appropriate. For example:

- when CPR will not restart heart and breathing;
- where death is imminent and life can only be restored for a short time or where patient will have no awareness and therefore no ability to experience benefit;
- where burdens outweigh benefits such as injuries from the CPR itself (fractured ribs and sternum, ruptured spleen).¹⁵

While both the DNR guidelines and guidelines for withdrawing treatment are helpful in setting out criteria for decision making, they do give the balance of power and authority to health care providers and provide few mechanisms for challenging the health care provider's decision. This may perhaps reflect a more paternalistic approach to the physician-patient relationship in England compared to Canada, which has moved towards greater patient autonomy.

B. UNITED STATES

The law relating to withholding and withdrawing of life sustaining treatment in the United States suffers from the same lack of clarity as that in Canada and England. Each state is responsible for the regulation of health care and may approach regulation of end-of-life decision making within DNR, advance directive or other legislation. The national legislative picture looks like a patchwork quilt with many similarities and differences between the various states.

In most states with legislation, there is an attempt to maximize the patient's right of autonomy; however, this is often limited by legislative deference to the health care providers expertise, particularly in making treatment decisions.

A number of states have enacted legislation which give health care providers authority to refuse requests for futile care. For example, Virginia's *Health Care Decisions Act*¹⁶ provides that health care providers are not required to provide medical treatment which is, in their opinion, medically or ethically inappropriate. This would appear to give health care providers the authority to withhold or withdraw treatment although it has, in at least one case, been held to be subordinate

¹⁵British Medical Association, "Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (U.K.), and the Royal College of Nursing" (March, 2001), online: <<http://bma.org.uk>> (date accessed: 7 May 2002).

¹⁶*Virginia Code*, § 54-1-2990.

to federal legislation which prohibits discrimination in treatment.¹⁷

The *Uniform Health-Care Decisions Act*,¹⁸ which has been adopted in whole or in part by Maine, New Mexico, Mississippi and Delaware provides that health care providers may refuse to comply with an advance directive that "requires medically ineffective health care or health care contrary to generally accepted health-care standards applicable to the health care provider or institution.

At least 11 states permit requests for treatment in an advance directive.¹⁹ Indiana and North Dakota recognize a legal right to receive medical treatment which can be communicated by either a "Life Prolonging Procedures Declaration" or a living will.²⁰ Indiana expressly permits requests for artificial nutrition and hydration "even if the effort to sustain life is futile or excessively burdensome."²¹ Pripp and Moretti question whether the legislated right to request life-sustaining treatment creates the corresponding legal obligation to provide such treatment.

Although it is unlikely that advance directive statutes would be interpreted as creating a positive right to receive any and all treatment, the legislatures that enacted these laws, as well as the individuals who rely on them, most likely believe they are protecting the patient's decision to be kept alive.²²

Legislation might create a right to ask for treatment but so far, it has not clearly created a corresponding obligation to provide it.

At least 27 states have DNR legislation,²³ the primary focus of which is to facilitate patient refusal of treatment and to protect and promote physician compliance with the request to terminate treatment. Most statutes provide for a presumption of consent to CPR unless a DNR order is made

¹⁷Health Care Ethics Consortium of Georgia, *1997 Task Force on Futility Report* (January 1997) 4 (hereinafter referred to as "HCECG Futility Report"), online: <<http://www.hcecg.org>> (date accessed: 7 May 2002).

¹⁸National Conference of Commissioners on Uniform State Laws, *Uniform Health Care Decisions Act* (1993) s. 7(f) and commentary, on line: University of Pennsylvania Law School Homepage, <<http://www.law.upenn.edu/bll/ulc/fnact99/1990s/uhcda93.htm>> (date accessed: 8 May 2002).

¹⁹W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 146, note 10: Arizona, Idaho, Indiana, Kentucky, Maryland, Minnesota, North Dakota, Oregon, Pennsylvania, South Dakota, Wisconsin.

²⁰*Living Wills and Life-Prolonging Procedure Act, Indiana Code* §16-36-4. See also: Manitoba League for Persons with Disabilities, *The Will to Live Template Project: A Discussion among People with Disabilities in Manitoba about the Right to Medical Care* (March 2002).

²¹W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 147.

²²W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 143.

²³W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 144.

in accordance with the legislation. Most states require the consent of the patient as a pre-requisite to DNR orders. At first glance, this appears to give patients a right to demand CPR; however, some states (New York, Virginia and Georgia) provide an exception to the consent requirement where treatment is futile. Most statutes attempt to restrict futility to the physiological futility formulation.

New York's *Public Health Law*²⁴ (PHL) offers an interesting example of legislative guidelines to end-of-life decision making and the resolution of disputes. The PHL provides for a presumption of consent to CPR unless there is a DNR order in place. Consent is a pre-requisite to a DNR order and the patient may impose "conditions" which must be satisfied before the DNR will be effective, permitting the patient to provide for limited or circumstance-specific DNR order.

Physicians can invoke therapeutic privilege to issue DNR orders without consulting the patient where discussing CPR would cause "immediate and severe injury". The PHL sets out guidelines and safeguards which the physician must follow before and after issuing the DNR order including:

- obtaining a second medical opinion before issuing the order;
- ascertaining the patient's wishes as much as possible without discussing CPR;
- recording the reasons for not consulting the patient;
- where possible, obtaining the consent of someone who would be authorized to give consent if the patient were incompetent;
- monitoring the patient's condition and promptly consulting the patient when discussing CPR no longer threatens the patient's well being.

In the case of an incompetent patient without a surrogate decision-maker or where the surrogate does not want to decide, a physician can issue a DNR order without consent when he or she believes "with a reasonable degree of medical certainty, [that] resuscitation would be medically futile". The physician must obtain a second consistent opinion or a court order. "Medically futile" is defined on a physiological basis; that CPR will not restore function or that the patient will suffer an arrest again soon after.

The PHL requires that DNR orders be reviewed at least every 7 days for hospital patients and every 60 days for patients in residential health care facilities.

Hospitals are required to establish mediation systems to resolve disputes and the PHL provides for judicial review of decisions to issue DNR orders. Those challenging a DNR order must show that it is contrary to the patient's wishes or best interests.

The United States federal government also has some limited jurisdiction with respect to health care and some federal statutes touch on end-of-life decision making. The federal *Patient Self-*

²⁴*Public Health Law*, Article 29B, §2962. Information regarding the *Public Health Law* may be found online: Medical Society of the State of New York Homepage, <http://www.mssny.org/members_only/legal/Legal_Guide/DNR.htm> (last modified 22 Nov. 1999).

*Determination Act, 1990*²⁵ requires that all health care facilities receiving Medicare or Medicaid funds inform patients of their right to accept or refuse medical treatment, any right under state law to make an advance directive, and the facility's policy regarding withholding or withdrawing of life-sustaining treatment.

The Act does not create a right to receive treatment but rather a right to "know" the manner in which decisions are made. Health care facilities must provide the patient with the information necessary to exercise autonomy in health care decision making.²⁶ This legislation has broad application because most health care facilities receive Medicare or Medicaid funding.

The *Emergency Treatment and Active Labor Act* (EMTALA) was enacted to prevent "patient dumping", a practice in which health care providers refuse to treat patients who receive Medicare or Medicaid funding or who transfer such patients before their condition is stabilized.²⁷ In *Matter of Baby K*²⁸ (discussed below), the 4th Circuit Court relied on the EMTALA to compel treatment of a disabled child despite state legislation which permitted withholding treatment on grounds of futility.

American case law has not yet directly addressed the issue of who, as between the health care provider and the patient, has the right to decide whether to withdraw or withhold life-sustaining treatment. Two cases which involved disputes between health care providers and patients were decided on other grounds.

In the case of *In re Helga Wanglie*,²⁹ the hospital and husband of the patient disagreed about the termination of life support. The hospital applied to replace the husband as the patient's legal guardian but the Court refused to do so as there was no evidence that Mr. Wanglie was not competent to act in his wife's best interest.

In *Matter of Baby K*, the Court held that the EMTALA took precedence over state legislation which authorized the termination of medically or ethically inappropriate treatment. Baby K was born with anencephaly, a condition in which a large part of the brain is missing. Baby K's mother, on religious grounds, insisted on aggressive life-sustaining treatment, contrary to the advice of health care providers who recommended a DNR order and "comfort care". Baby K was eventually weaned from a respirator and transferred to a nursing home although she had to be taken to the emergency

²⁵*Patient Self-Determination Act of 1990*, §§4206 and 4751 of *Omnibus Reconciliation Act of 1990*, Pub. L. No. 101-508 (Nov. 5, 1990).

²⁶L.P. Ulrich, *The Patient Self-Determination Act: Meeting the Challenges in Patient Care* (1999) 185.

²⁷W. Pripp and M. Moretti, "Medical Futility: A legal perspective" in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 136 at 142, note 8.

²⁸*Matter of Baby K*, 16 F.3d 590 (4th Cir. 1994).

²⁹*In re Helga Wanglie*, Fourth Judicial District (Dist. Ct. Probate Ct. Div.) PX-91-283, Minnesota, Hennepin County (July 1991).

department several times to deal with respiratory difficulties.

The hospital applied for a declaration that it did not have to administer ventilator support to Baby K. The Court refused to grant the order holding that refusing treatment was discrimination on the ground of disability contrary to the EMTALA. While the effect of the decision was to provide treatment, the case was not decided on the basis that the patient has the right to insist on such treatment.

C. CONCLUSION

Unfortunately, we cannot look to either England or the United States for guidance as neither has established clear legislative guidelines governing the withdrawal of life sustaining treatment.

CHAPTER 4

MAKING DECISIONS TO WITHDRAW OR WITHHOLD LIFE-SUSTAINING TREATMENT

A. MEDICAL ETHICS AND THE PHYSICIAN-PATIENT RELATIONSHIP

Health care providers (usually physicians) control access to the publicly funded health care system, and therefore carry great authority and responsibility. While most Canadians trust and respect physicians,¹ as a society we have come to question the exercise of any authority over the individual.

Our history and experience tell us that human beings are not perfect in their exercise of power over others. When one person has the power to exercise a discretion or make a decision which impacts the life of another, there is always the potential for mistakes or even abuse. The inappropriate exercise of power may be conscious and deliberate or quite unintentional but the harm caused is serious regardless.

As a society, safeguarding against the improper exercise of authority in a decision-making process often involves ensuring transparency in that process as well as providing a form of accountability for the decision-maker. Dissatisfaction with the current system of end-of-life decision making may, in part, stem from a lack of transparency and accountability.

As discussed earlier, there are no statutory or common law rules which regulate end-of-life decision-making. The Government of Manitoba, which has primary constitutional authority for health care, has delegated much of its authority for regulating the medical profession and the practice of medicine to the College of Physicians and Surgeons of Manitoba ("the College"). The College has established a *Code of Conduct*.² which sets out ethical principles that physicians must follow in medical practice. The College has also established guidelines on various topics (including one for DNR orders).³ A guideline is not binding, it is a "generally recommended" practice, and establishes a benchmark of acceptable practice. Both the Code of Conduct and Guideline 151 (DNR Orders) support a physician's authority to withhold treatment.

Section 1 of the Code of Conduct requires health care providers to "consider first the well

¹Canadian Press, "Firefighters, nurses top list of most trusted", *Winnipeg Free Press*, February 25, 2002.

²The College of Physicians and Surgeons of Manitoba, *Code of Conduct*, online: <http://www.umanitoba.ca/colleges/cps/Code/index_code.html> (date accessed: 8 May 2002).

³The College of Physicians and Surgeons of Manitoba, Guideline 151 ("*Do Not Resuscitate*" and *Supportive Treatment Orders* (currently under review), online: <http://www.umanitoba.ca/colleges/cps/Guidelines_and_Statements/151.html> (date accessed: 8 May 2002).

being of the patient." Guideline 119 (The Doctor/Patient Relationship) elaborates on this principle and suggests that consideration of the patient's well being requires a balancing of the following principles:

- Beneficence* the capacity to have a good effect
- Maleficence* the capacity to have a bad effect
- Autonomy* the freedom of the individual to self-determine
- Justice* the inherent equity given the specific capabilities of the individual

Guideline 119 goes on to describe the ideal doctor/patient relationship as one in which "beneficence is optimized and maleficence is minimized with all decisions being just and respecting patient autonomy." The power to withhold treatments is grounded in this "primary ethical principle".

Section 19 of the Code states that "[t]reatments that offer no *benefit* and serve only to prolong the dying process should not be employed" (emphasis added). Benefit is not defined and may not be capable of precise definition. In cases of conflict, it may be the determination of what constitutes a benefit that is problematic. In terms of including patients in the decision making process, section 19 also requires that health care providers *make an effort* to explain the non-provision of futile treatments to patients and families *when appropriate*. The Code of Conduct does not require patient consent as a pre-requisite to withdrawing treatment. Instead, a health care provider must "ascertain wherever possible and recognize" the patient's wishes about life-sustaining treatment (section 17). The DNR guideline is vague and confusing to the lay person and does not clearly address patient input in decision making. It does not address how disputes should be resolved. The College is currently reviewing this guideline and it will likely be amended in the future.

There are also two "national" professional guidelines which address DNR orders and resolution of disputes. The *Joint Statement on Resuscitative Interventions*,⁴ and the *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*⁵ establish a benchmark of acceptable practice for the profession. The *Joint Statement on Resuscitative Interventions* provides more detailed guidelines than the College's DNR guideline and addresses the need for conflict resolution mechanisms. It states (at page 1652A) that there is no obligation to offer "futile or non-beneficial" treatment but recognizes that these are "controversial concepts when applied to CPR". It considers a treatment to be futile when "it offers

⁴Canadian Medical Association, *et al*, "Joint Statement on Resuscitative Interventions" (1995), 153 CMAJ 1652A.

⁵Canadian Healthcare Association, *et al* "Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care" (June 15, 1999), on line: <<http://www.canadian-healthcare.org/documents/joint.htm>> (date accessed: 7 May 2002).

no reasonable hope of recovery and improvement or because the person is unable to experience any benefit". Although the Joint Statement's definition appears to be one of physiological futility, the words "reasonable" and "benefit" are often matters of opinion on which reasonable people can, and do, disagree. This suggests some element of qualitative futility as will be discussed below.

All of the existing guidelines respecting decisions to withhold or withdraw treatment are mainly written for and by the medical profession and may not incorporate perspectives of the broader community or other stakeholders. Transparency and accountability in the decision making process might be improved by greater community input to guidelines.

QUESTIONS FOR DISCUSSION

At the end of Chapter 2, we asked what should rules to govern end-of-life decision-making look like. Our next question is:

Question 2: How do we make these new rules?

- (a) Who should be involved in creating the rules?
- (b) What process or processes should be used?

B. DECIDING ON THE BASIS OF FUTILITY

What does it mean when we say treatment is futile? There is no consensus on the meaning of medical futility, as evidenced by the substantial body of literature on the subject. As Professor Barney Sneiderman points out

With the exception of the debate over the proposed legalization of physician-assisted suicide and voluntary euthanasia, no topic in the bioethics literature has provoked more soul-searching and controversy than that of medical futility....⁶

Judgments of futility are controversial because they often require a consideration and selection of values. This leads to the question: "Whose values should govern?"

Categorizing a treatment as futile could mean that it will not work (physiological futility) or that it is not worth doing (qualitative futility)⁷ If CPR cannot restore pulse or breathing, it is physiologically futile. If CPR will restore pulse and breathing but cannot restore consciousness, it is qualitatively futile.

⁶B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba v. R.L. and S.L.H.*" (1999), 7 Health L.J. 205 at 209.

⁷See definition of futility at page 3.

In general, judgments of physiological futility are considered to require pure clinical judgments and therefore cannot be challenged by the patient. This "privileging" of physiological futility judgments has resulted in the idea that health care providers may withdraw life-sustaining treatment without consent. Only the health care provider can judge whether a treatment is physiologically futile. Once its futility is established, the health care provider is under no duty to provide a treatment. If there is no duty to provide it, then consent is not required.

Qualitative futility judgments, on the other hand, involve decisions about what is worthwhile. Health care providers are expert at deciding whether a particular treatment will achieve a particular outcome. In the current understanding of medical futility, patients are expert at deciding whether that outcome is "good" from their point of view. Two patients in the same situation may arrive at different conclusions about whether the outcome of a proposed treatment is acceptable. For example, a person with a strong belief in the sanctity of life may request life-sustaining treatment while another may want treatment withheld so that they will not linger.

In her book, *When Doctors Say No: The Battleground of Medical Futility*,⁸ Susan Rubin challenges the privileging of physiological futility judgments and rejects the presumption that such judgments are "value-free". She suggests that the exercise of clinical judgment will always entail consideration and selection of values at some point.

First, we cannot avoid subjectivity in the analytical process as everyone looks at the world through the "lens" of their own values, experience and attitudes⁹. This lens of experience affects how we perceive and analyze data and even how we frame the question in the first place. In other words, a health care provider's own religious views and other values will affect the manner in which they assess a patient's condition and determine which treatments are appropriate.

Second, medicine is not an exact science and there is much disagreement within the medical profession about diagnoses and treatment. As the medical profession learns more about disease and treatment, earlier views and practices may be rejected.¹⁰

Whether a given treatment is "beneficial" may be controversial both scientifically and philosophically. There is much debate within the scientific community over what constitutes an agreed-upon standard or range of goals for a particular disease and the alternative treatment options to be considered. Standards of practice are frequently subject to question as the outcome data are often not available or inconclusive. Therefore, much uncertainty exists about the prognosis for certain diseases and the projected efficacy of alternative treatments. Professional societies' statements may offer conflicting views of what constitutes "futile treatment" which physicians are "under no obligation" to offer. In addition, there may be great variation in how individual clinicians within the same specialty assess

⁸S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998).

⁹S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 96-101.

¹⁰S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 60 and 110.

beneficiality and communicate their assessments to patients or their surrogates.¹¹

Determining the appropriate measure of success in order to assess the effectiveness of treatment can be problematic and may also require a selection of values. If a treatment has failed in the last 99/100 cases, it may be rejected even though the patient who survives would likely consider the treatment worth doing.¹²

The statistical cutoff point chosen ... as the threshold for determining futility is relative to opinion. Why not, three percent, or five percent (as is customarily adopted in scientific research)? No matter what point is selected, there is always a potential survivor not predicted to survive, prompting the public and the courts to spend vast quantities of scarce resources to avoid the possibility of that survivor expiring. Even if there was agreement on a statistical cutoff point for determining futility, physicians are often highly unreliable in estimating the likelihood of success of a therapeutic intervention. Even in theory, statistical inferences about what might happen to groups of patients do not permit accurate predictions of what might happen to the next patient.¹³

Third, judgments of physiological futility will require reference to and selection of values when identifying the appropriate goals of treatment. When we say CPR will not work, we must first consider what it is that we are trying to achieve. If the desired outcome is eventual discharge from the hospital, CPR may be futile. If the goal is to restore some degree of function or to extend the patient's life for a short time, then CPR may not be futile. Whether or not a treatment is "futile" depends on the goal selected. The selection of goals requires a value judgment.¹⁴

The line between physiological and qualitative futility can be very fine and an opinion about the qualitative futility of a particular treatment may "creep in" to the determination of its physiological futility. In *Sawatsky*, the physician's evidence in support of the DNR order demonstrated a mingling of physiological and qualitative futility. The physician opined that the CPR *probably* would not work (physiological futility) but also that, even if it did work, it would not be worthwhile (qualitative futility) because of the harm it would *probably* cause.

... given Mr. Sawatsky's health condition, it is improbable that, even if initiated cardiopulmonary resuscitation would succeed. If cardiopulmonary resuscitation did succeed, it is very probable that the most it would serve is to keep Mr. Sawatsky on a life-support system. In the unlikely event that Mr. Sawatsky was successfully removed from life-support, particularly considering his current level of brain impairment, it is very likely that he would be left with additional brain damage, and in a

¹¹Health Care Ethics Consortium of Georgia, *1997 Task Force on Futility Report* (January 1997) 2 (hereinafter referred to as "HCECG Futility Report"), online: <<http://www.hcecg.org>> (date accessed: 7 May 2002).

¹²S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 61-62.

¹³L. Olmsted, "Medical Futility", on line: <<http://www.wramc.amedd.army.mil/departments/Judge/futility.htm>> (date accessed: 7 May 2002).

¹⁴S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 88 and 101-102.

persistent vegetative state.¹⁵

Olmsted suggests that futility itself "generally fails to provide an ethically coherent ground for limiting life-sustaining treatment"¹⁶ and that the approach to end-of-life decision making should be based upon the interests of the patient.

Rubin not only argues that decisions to withdraw treatment should not be based on futility but also that futility should not be used to justify what she calls "physician unilateral decision making". She advocates for more meaningful patient participation in end-of-life decisions.

I have contended that physician unilateral decision making is an excessive and unnecessarily harsh solution to the problem of futility. The practice of physician unilateral decision making damages the trust that is essential to a successful therapeutic relationship between patients and their care providers. Moreover, physician unilateral decision making misconstrues the very grounding of the physician-patient relationship. At its worst, physician unilateral decision making constitutes an unjustified violation of patient autonomy, a return to the oldest form of unjustified paternalism, an unjustified generalization of physician expertise, a breach of the contract between the medical profession and society, and an unwarranted exercise of power.¹⁷

1. Why Do Patients Request Futile Treatment?

There are many reasons why a patient might request life-sustaining treatment which is futile. The patient may want to live longer in order to make arrangements or say good-bye to family. Some believe that a miracle may occur. The patient's deeply held moral or religious belief in the sanctity of life may require that he or she do everything possible to prolong life.

Sometimes, the demand for treatment comes from unrealistic expectations about the potential outcome. An Australian study¹⁸ of patient attitudes to CPR showed a generally poor knowledge of the success rate of CPR. The study suggested that the cause of unrealistic expectations was inaccurate information from television, books, magazines and public information which tends to emphasize the benefits of CPR and not the risks. Once patients received accurate information about CPR, its success rate and the side effects, they changed their minds about wanting CPR.

¹⁵Affidavit of Dr. Boutscha, quoted in *Do Not Resuscitate Orders and the Law in Canada -- Patient's Rights* (October 2000) 27 (a paper prepared for the Manitoba League of Persons with Disabilities by Sherri Walsh, LL.B.).

¹⁶L. Olmsted, "Medical Futility", on line: <<http://www.wramc.amedd.army.mil/departments/Judge/futility.htm>> (date accessed: 7 May 2002).

¹⁷S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 117.

¹⁸I. Kerridge, S.A. Pearson, I. Rolfe, M. Lowe and J. McPhee, "Impact of Written Information on Knowledge and Preferences for Cardiopulmonary Resuscitation" (1999) 171 *Med. J. Aust.* 239-242.

Fear, guilt, denial, grief, anger and so many other emotions that naturally accompany a life-threatening condition or crisis will affect a patient's desire for treatment. For the family of the patient, making a decision to withdraw or withhold care can seem tantamount to causing the death of their child, parent or sibling. A difficult family dynamic may further complicate decision-making when there are unresolved emotional issues or when family members cannot agree.

In a recent newspaper article on palliative care, Margaret Clarke, executive director of Hospice and Palliative Care Manitoba, is quoted as saying "We have been conditioned to believe that with all the cures and treatments that we can live forever." Canadians, she suggests, are "reluctant to admit that their lives will end and try to keep death at arm's length for as long as possible".¹⁹

Health care providers may also find it difficult to discuss death with patients, particularly patients who are young or who are unknown to them. A study of 10 family physicians²⁰ found that raising the issue of DNR orders was challenging for physicians. Their own uneasiness about death and fear of damaging their patient's trust was a barrier to communication. Additional pressure is created when there is conflict within the patient's family.

Our study echoes a number of themes in the literature. Discomfort with the topic of death, time constraints, discontinuity of physician care between outpatient and hospital settings, and concern about patient and family reactions have been cited as barriers to physician-initiated discussions about advance directives....attending physicians' and residents' comfort with discussing death, experiences with death and dying, ability to "let go" of the patient and personal knowledge of the patient influenced their approach to code-status decision-making.²¹

In some cultures and religions, a belief in the sanctity of life and an obligation to do everything possible to maintain life may prompt requests for life-sustaining treatment. Fears of racial or cultural discrimination may also affect how people react to a proposal to withdraw or withhold treatment. For members of historically disadvantaged groups, distrust of those in authority may contribute to demands for life-sustaining treatment.

African Americans who enter the primary care setting are three times more likely than Caucasians to desire more end-of-life care. This may result in part from more strongly held religious beliefs and faith in miracles, but there also appears to be a strong expectation of inadequate care because

¹⁹P. Samyn, "Compassionate Journey", *Winnipeg Free Press*, Thursday, February 28, 2002, A10.

²⁰B. Calam, S. Far, R. Andrew, "Discussions of 'code status' on a family practice teaching ward: What barriers do family physicians face?" (2000), 163(10) C.M.A.J. 1255.

²¹B. Calam, S. Far, R. Andrew, "Discussions of 'code status' on a family practice teaching ward: What barriers do family physicians face?" (2000), 163(10) C.M.A.J. 1255 at 1258.

of race.²²

2. Futility and the Disabled

In *Lavallee*, the Manitoba Court of Appeal decided that prolonging the life of a patient in a permanent vegetative state was not worthwhile, a position we see repeated by the House of Lords in *Bland* and by the Supreme Court of Canada in *Rodriguez*. In *Rodriguez*, the Supreme Court recognized sanctity of life to be a principle of fundamental justice but also recognized that it was not an absolute. The Court found that diminished quality of life may be an exception to the principle of sanctity of life.

Quality of life is not a concept which can be defined with precision. It varies greatly from person to person and may change for any given person. While an able bodied person might think they would have significantly diminished quality of life if they were to become disabled, they might change that view if they do become disabled and are still able to enjoy life.

Advocates for the disabled challenge decision making on the basis of "quality of life" considerations. Past experience has shown them the personal beliefs of physicians and decision-makers about their quality of life will have a negative or discriminatory effect on the disabled. Chief Justice Lamer (as he then was) commented on this "devaluation" of the lives of the disabled in his dissent to *Rodriguez*,

Sadly, increasingly less value appears to be placed in our society on the lives of those who, for reasons of illness, age or disability, can no longer control the use of their bodies.²³

Health care providers who project their own values and attitudes about quality of life into the decision making process may withdraw or withhold treatment prematurely. Thoughts of "I would not want to live like that" may turn to "You must not want to live like that" which may, in turn result in a decision that "you should not live". While some may agree with Professor Sneiderman that "it is pointless, dehumanizing, and a waste of resources to maintain the life of a PVS [permanent vegetative state] patient"²⁴ or that it is appropriate to withhold life sustaining treatment from a person in the end stages of a terminal illness, these are by no means universal views. Bioethicist Dr. Charles Weijer has challenged the assertion that it is appropriate to withdraw life-support from a patient in a permanent vegetative state suggesting that such a decision does not depend on whether treatment will work but rather on deciding what kind of life

²²M.F. Morrison and S. Gelbach Demichele, "How culture and religion affect attitudes toward medical futility", in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 71 at 78.

²³*Rodriguez v. British Columbia (Attorney General)*, [1993] 3 S.C.R. 519 at 565.

²⁴B. Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the *Case of Child and Family Services of Central Manitoba v. R.L. and S.L.H.*" (1999), 7 Health L.J. 205 at 211.

is worth preserving.²⁵

In its paper entitled, *Our Last Rights: Do Not Resuscitate Orders and People with Disabilities*,²⁶ the Manitoba League for Persons with Disabilities gives examples of the impact of negative attitudes and stereotypes about the value and quality of life of the disabled on medical decision making. In essence, discriminatory attitudes and beliefs about the disabled result in treatment decisions that, implicitly, say that the lives of disabled people are not worth preserving.

The benefits of a transparent decision making process and a dispute resolution system may become particularly important for patients who are historically disadvantaged in society. Reducing the exercise of individual discretion would also reduce vulnerability to decision makers with discriminatory attitudes and beliefs.

3. Futility and the Elderly

Age Concern, an advocacy organization for the elderly, has raised the alarm about age discrimination by the National Health Service in England. Patients reported that they were told that they were too old for treatment, were not told about particular treatments, received a lower quality of care or were assigned a low priority.²⁷

The elderly in England have expressed concerns that they are being left to die with little regard to their potential for an enjoyable or meaningful (to the patient) life. Most people not only want to make the most of their remaining years but want to maximize the number of remaining years as well.

Inadequate health care for the elderly is already an issue in Canada. With our aging population and an already over-taxed health care system, examples of inappropriate or premature decisions to withhold or withdraw care may increase.

4. Religion, Culture and Race

Canada's population comprises a broad diversity of culture, religion and language. There

²⁵C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ: 491 at 493.

²⁶R. Wiebe, *Our Last Rights: Do Not Resuscitate (DNR) Orders and People with Disabilities* (MPLD, 2000) 78-86.

²⁷Age Concern, online: <<http://www.ageconcern.org.uk/>> (date accessed: 9 May 2002).

is a wide range of views regarding end-of-life care and decision making between and within cultural and religious groups.

Charles Weijer argues that it is unethical to withdraw or withhold life-sustaining treatment from patients whose religious views, such as Orthodox Judaism, Protestant Fundamentalism and conservative Catholicism, include "a deeply rooted belief in the sanctity of life, a belief in the God-given sacredness of human life". In the case of Orthodox Judaism, there may be an obligation to "seek out and accept life-prolonging treatment."²⁸

Even though patients in a PVS lack the capacity for suffering, they must be treated with dignity. Is the provision of CPR to patients in a PVS an indignity? Dignity is sensitive to the particulars of the situation. For example, kneeling is an indignity if I require it of my research assistant in my presence; it is not an indignity if it is required as part of his religious observances. Similarly, CPR in cases of PVS may indeed be an indignity to those who do not believe in the sanctity of life. Yet it may not be an indignity to those who in receiving treatment are fulfilling an obligation to their God. Thus, a valid evaluation of dignity must be sensitive to the cultural and religious context of the patient, and physicians must be careful not to project their own culturally biased assessment on patients of different backgrounds.²⁹

"Cultural and religious differences between the patient and the medical team are an underappreciated barrier to negotiating a sensitive and dignified process of dying for the patient."³⁰ For example, in some Aboriginal and Asian cultures, discussing death *with the patient* is believed to hasten death. It is therefore appropriate for the *patient's family* to receive information and make decisions in order to protect the patient from harm.

Direct, unmediated communication of "bad news" involving terminal prognosis or risks of impending death may violate some individual's and community's values. Cultural and spiritual traditions, including those of Navajo people in the United States and Dene people in Canada, assert that speaking explicitly about terminal illness and death may hasten death. Some families may therefore ask to be present to mediate the communication of bad news and support the family.³¹

The Euro-Canadian focus on full disclosure and individual autonomy will conflict with some cultural traditions and cause harm.

In times of crisis and when facing one's own mortality, religious and familial/cultural values are

²⁸C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ 491 at 492.

²⁹C. Weijer, "Cardiopulmonary Resuscitation for Patients in a Persistent Vegetative State: Futile or Acceptable?" (1998), 158 CMAJ 491 at 492.

³⁰M.F. Morrison and S. Gelbach Demichele, "How culture and religion affect attitudes toward medical futility", in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 71 at 71.

³¹J. Ellerby, J. McKenzie, S. McKay, G. Garipey, J. Kaufert, "Bioethics for Clinicians: 18 Aboriginal Cultures" (2000), 163 C.M.A.J. 846 at 847.

sources of strength and comfort. Recently, authors have disagreed about whether the Western emphasis on autonomy and full disclosure is respectful of dying patients with different cultural traditions. In the Asian, Hispanic, and other traditions, autonomy must be balanced against such values as family and community support and compassion. Full disclosure may be at variance with cultural beliefs about hope and wellness, and autonomous decision making may counter family-centered values.... The patient's values determine whether it is beneficial or burdensome to be fully informed.³²

Thus it is not just the decisions themselves which may be culturally or spiritually inappropriate for the patient, but the process of arriving at the decision which may also offend cultural and religious beliefs.

Our health care system may not reflect Canada's cultural or religious diversity. Mainstream medicine has been slow to incorporate diverse cultural practices. One example of conflict between a generally accepted medical concept and the cultural and religious beliefs of some Canadians may be found in the medical definition of death. At common law, death is defined as the "irreversible cessation of cardiopulmonary functioning"³³ (heartbeat and breathing). It is possible to maintain heart and lung function artificially so that a patient who has no brain function would still be legally alive. The medical profession developed the concept of "brain death" which has now been accepted as the legal standard of death in most US states and in Manitoba.³⁴ Even without legislative acceptance, physicians in other provinces follow the brain death standard pursuant to Canadian Medical Association guidelines and not the common law definition of death.³⁵

While the brain death standard may be appropriate for many, it will offend people whose culture or religion includes a belief in the absolute sanctity of life and the obligation to preserve life at all costs. Accepting the brain death standard is not simply a medical decision but is a social and moral decision which reflects the beliefs of the dominant culture.

The advent of neurologic or brain death criteria to establish the death of a person was a significant departure from the traditional way of defining death and remains ethically challenging. However, regardless of which criteria are used, agreement about when death occurs is not simply an agreement about medical or biological criteria for death but is also a "social formulation."³⁶

³²M.F. Morrison and S. Gelbach Demichele, "How culture and religion affect attitudes toward medical futility", in M.B. Zucker and H.C. Zucker, eds., *Medical Futility and the evaluation of life-sustaining interventions* (1997) 71 at 71.

³³B. Sneiderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (2nd ed., 1995) 327.

³⁴*The Vital Statistics Act*, C.C.S.M. c. V60, s. 2.

³⁵B. Sneiderman, J.C. Irvine and P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (2nd ed., 1995) 327.

³⁶N. M. Lazar, S. Shemie, G.C. Webster, B.M. Dickens, *Bioethics for clinicians: 24. Brain death* (2001) 164(6) CMAJ 833-836.

New Jersey has responded to this concern by providing for a religious exception to the brain death standard. New York has, by regulation, encouraged recognition of religious views in the legal determination of death. It is therefore possible, in "fill[ing] the gap between old law and new medicine"³⁷ to provide a legislative response which allows for accommodation of religious or cultural diversity.

QUESTIONS FOR DISCUSSION

Earlier in this paper, we asked what form rules should take and what process should be followed to create them. Now we ask:

Question 3: What should the rules be?

- (a) Should health care providers be required to obtain a patient's consent before withholding or withdrawing treatment?
- (b) If yes, should there be limits to the requirement to obtain consent? What should the limits be?
- (c) If consent is not required, who should decide to withhold or withdraw treatment?
- (d) What criteria should be followed in making such decisions?
- (e) If consent is not required, how can patients' wishes and interests be honoured and protected?
- (f) If decisions to withhold or withdraw treatment are based on "futility", should a legal definition of futility be established?

Question 4: How should disputes be resolved?

- (a) What should a dispute resolution process look like? Should it be informal or formal? Mediation, arbitration or court application?
- (b) Who should administer the dispute resolution process - health care providers or an independent agency?
- (c) Who should be responsible for funding and administering the process?

³⁷ *Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 at 888 (H.L.) per Lord Mustill.

C. DNR POLICIES IN MANITOBA

In 1997, the Manitoba Government delegated some authority for health care policy, planning and service delivery to 12 Regional Health Authorities (RHA).³⁸ Together, these regional health authorities manage Manitoba's 78 hospitals, 116 personal care homes and 28 community health centres/clinics.³⁹

In 2000, the Manitoba League for Persons with Disabilities (MPLD) surveyed Manitoba RHAs and a sampling of 26 rural and urban hospitals and long term care facilities with respect to their DNR order policies and practices.⁴⁰ The responses show that there is inconsistency across Manitoba in DNR order policies. Some RHAs and facilities did not have DNR order policies or were developing policies. For the RHAs and facilities which did have policies, there were significant differences in the policies, particularly within the Winnipeg Regional Health Authority.

Three Manitoba RHAs had a policy governing the placement of DNR orders although each was somewhat different. The remaining RHAs had no policy or were developing policy. Three regions ((Burntwood, Brandon, Dauphin) required patient's consent for DNR orders while one region encouraged consent (Winnipeg), another left it up to each institution (Parkland) and the others were developing policy.

Policies which did not require consent to DNR orders typically did not impose an obligation to advise the patient of the DNR order and had no dispute resolution process in place to resolve disagreements.

The WRHA encourages facilities to obtain consent for and advise patients of DNR orders. There are differences in policy between various health care facilities in the WHRA. For example, the Health Sciences Centre and the St. Boniface Hospitals require patient consent as a pre-requisite to DNR orders, Seven Oaks recommends consent, Victoria General Hospital requires consultation and Riverview Health Centre has an automatic DNR order placed upon admission.

Manitobans may not realize that there are policy differences between various health care institutions. This gives rise to the following questions:

QUESTIONS FOR DISCUSSION

³⁸The *Regional Health Authorities Act*, C.C.S.M. c. R34.

³⁹Manitoba Health, *Region Index for Regional Health Authorities*, (December 15, 1999), online: <<http://www.gov.mb.ca/health/rha/commreg.pdf>> (date accessed: 8 May 2002).

⁴⁰R. Wiebe, *Our Last Rights: Do Not Resuscitate (DNR) Orders and People with Disabilities* (MPLD, 2000) 47-64.

Question 5: Should health care facilities' policies governing withdrawing and withholding of care be mandatory?

- (a) Should policies be consistent or have certain mandatory requirements?
- (b) Should policies be determined
 - (I) at the provincial level (for all institutions)?
 - (ii) at the regional level (RHA)?
 - (iii) at the institutional level?
- (c) Should there be different types of policies depending upon the nature of the health care facility?
- (d) Are automatic DNR policies appropriate? In what circumstances or for which kinds of facilities?

The Commission also invites health care providers (institutions and individuals) to provide information about their policies and practices governing the withdrawing and withholding of treatment.

D. ECONOMIC CONSIDERATIONS: SHOULD THEY BE RELEVANT?

Should scarcity of resources be a consideration in decisions to withhold or withdraw life-sustaining treatment? If a requested treatment is truly futile, should it be administered if it is inexpensive? Should effective treatments be provided regardless of the cost (assuming the treatment is reasonably accessible)? Even if there was general agreement that scarcity of resources should not be relevant to end-of-life decision making, the current debate about the continued viability of the health care system leads to the perception that a consideration of resources will factor into decisions to withdraw care. Thus, we must identify and confront the economic issues in this discussion.

In its position paper entitled *Establishing "Medically Required" and Core Services*,⁴¹ the British Columbia Medical Association (BCMA) considers the development of a "priority preference list of services." British Columbia's health care legislation, like Manitoba's, provides that "medically required" health care services are covered by the provincial health insurance plan but does not define what those services are. The BCMA suggests that

A decision to restrict the scope of services covered under health insurance must ultimately be a policy choice implemented by government, based on economic factors, public opinion and

⁴¹British Columbia Medical Association, "Establishing 'Medically Required' and Core Services" (April 2000), online: <<http://www.bcma.org/IssuesPolicy/IssueBackgrounders/medicallyrequired.asp>> (date accessed: 8 May 2002).

medical input. This decision is one of economic rationing, not of medical necessity.⁴²

Publicly funded health care systems around the world are facing the challenge of providing universal health care services and are responding by restricting the scope of available services. In England, the Court of Appeal declined to interfere with a health care authority's decision not to fund a third round of cancer treatment for a young patient. In that case, the treatment was very expensive and the chance of success was small.

I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet.... Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make.⁴³

QUESTIONS FOR DISCUSSION

Question 6: Should economic consideration be relevant? If so, how?

⁴²British Columbia Medical Association, "Establishing 'Medically Required' and Core Services" (April 2000) para. 1, online: <<http://www.bcma.org/IssuesPolicy/IssueBackgrounders/medicallyrequired.asp>> (date accessed: 8 May 2002).

⁴³*R. v. Cambridge Health Authority, Ex. p.B.*, [1995] 2 All E.R. 129 at 137 (C.A.).

CHAPTER 5

ISSUES FOR DISCUSSION

Most people want to die with dignity, a concept which implies a measure of control over the dying process. To be subject to the control of another person at such a critical time may cause distress and give rise to concerns that we will be "let go" when we are not ready or in a way that is inconsistent with our philosophical or spiritual beliefs.

While guidelines of the medical profession *recommend* that patients be consulted about decisions to withhold or withdraw treatment, there is no legal obligation to do so. Susan Rubin suggests consultation without the potential to influence the outcome is inappropriate.

The opportunity to participate must be genuine and meaningful. Merely disclosing the intent to deny treatment on the grounds of futility, putting patients on notice, or referencing professional position statements or institutional policies is insufficient if physicians ultimately have the power to make and implement treatment decisions on the basis of their judgments of futility. In such an approach concessions to patients constitute only lip service, not actual opportunities to influence, much less control, the decision making process.¹

It is perhaps this lack of control over what will happen which is the greatest source of dissatisfaction for patients and families affected by decisions to withhold treatment.

On the other hand, giving patients greater autonomy may infringe the health care provider's professional autonomy and integrity. Since resolution of this conflict requires a balancing of the rights and obligations of patients and health care providers, we must engage in a broad based social dialogue and seek a consensus on the scope of patient and physician autonomy in decisions to withdraw or withhold treatment.

The questions raised throughout the paper are reproduced here for ease of reference:

Question 1: What should be the nature or form of legal rules governing decisions to withdraw and withhold life-sustaining treatment?

For example:

- (a) legislative guidelines (statutes or regulations to existing or new legislation)?
- (b) amendments to existing professional guidelines?
- (c) other?

Question 2: How do we make these new rules?

¹S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (1998) 117.

- (a) Who should be involved in creating the rules?
- (b) What process or processes should be used?

Question 3: What should the rules be?

- (a) Should health care providers be required to obtain a patient's consent before withholding or withdrawing treatment?
- (b) If yes, should there be limits to the requirement to obtain consent? What should the limits be?
- (c) If consent is not required, who should decide to withhold or withdraw treatment?
- (d) What criteria should be followed in making such decisions?
- (e) If consent is not required, how can patients' wishes and interests be honoured and protected?
- (f) If decisions to withhold or withdraw treatment are based on "futility", should a legal definition of futility be established?

Question 4: How should disputes be resolved?

- (a) What should a dispute resolution process look like? Should it be informal or formal? Mediation, arbitration or court application?
- (b) Who should administer the dispute resolution process - health care providers or an independent agency?
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- (d) Are automatic DNR policies appropriate? In what circumstances or for which kinds of facilities?

The Commission also invites health care providers (institutions and individuals) to provide information about their policies and practices governing the withdrawing and withholding of treatment.

Question 6: Should economic consideration be relevant? If so, how?

The Commission also invites health care providers (institutions and institutions) to provide information about their policies and practices governing the withdrawing and withholding of treatment.